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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Agency for Healthcare Research and Quality

Request for Measures and Domains To Use in Development of a Standardized Instrument for Use in Public Reporting of the Quality of Transition from Child-focused to Adult-focused Care in Young Adults With Chronic Conditions

AGENCY: Agency for Healthcare Research and Quality (AHRQ), HHS.

ACTION: Notice of request for measures and domains.

SUMMARY: Section 401(a) of the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA), Public Law 111-3, amended the Social Security Act (the Act) to enact section 1139A (42 U.S.C. 1320b-9a). Section 1139A(b) charged the Department of Health and Human Services with improving pediatric health care quality measures. The Agency for Healthcare Research and Quality (AHRQ) is requesting the submission of instruments or domains (for example, key concepts) measuring aspects of the transition from child-focused to adult-focused care in young adults with chronic health conditions from all researchers, vendors, hospitals, stakeholders, and other interested parties. AHRQ is interested in instruments and items through which young adults or parent proxies may assess experiences they have with the health care system, including the transition from pediatric to adult health care. The goal is to develop a standardized instrument for use in assessing the quality of transition from child-focused to adult-focused care in young adults with chronic health conditions.

DATES: Please submit materials [WITHIN 30 DAYS OF PUBLICATION OF THIS NOTICE]. AHRQ will not respond to individual submissions, but will consider all suggestions.

ADDRESSES: Electronic submissions are encouraged, preferably as an email with an electronic file in a standard word processing format as an email attachment. Submissions may also be in the form of a letter to:

Maushami DeSoto, M.Sc., Ph.D., MHA.
Office of Extramural Research, Education and Priority Populations
Agency for Healthcare Research and Quality
540 Gaither Rd., Rockville, MD 20850
Phone: (301) 427-1546
Fax: (301) 427-1238
Email: Maushami.Desoto@AHRQ.hhs.gov

All submissions must include a written statement from the submitter that it will grant AHRQ the necessary rights to use, modify, and adapt the submitted instruments, domains, items, and their documentation for the development of this survey and its dissemination for AHRQ purposes. The statement must also address the instrument's proprietary and/or confidentiality status. In accordance with CHIPRA's charge to improve pediatric quality care measures, and consistent with AHRQ's mandate to disseminate research results, 42 U.S.C. 299c--3, AHRQ purposes include public disclosure and dissemination (e.g., on the AHRQ Web site) of AHRQ products and the results of AHRQ-sponsored research and activities. The written statement must be signed by the copyright holder or an individual authorized to act for any holder of copyright and/or data rights on each submitted measure or instrument. The authority of the signatory to provide such authorization should be described in the letter. If the submitted measure or instrument is selected for further development AHRQ will request that the submitter execute a license granting all of the above-referenced rights to the Department of Health and Human Services.

Submission Guidelines:

When submitting instruments, please include, to the extent that it is available:

- Name of the instrument;
- Copies of the full instrument, in all languages available;
- Domains or key concepts included in the instrument;
- Instrument reliability (internal consistency, test-retest, etc) and validity (content, construct, criterion-related);
- Results of cognitive testing;
- Results of field-testing;
- Current use of the instrument (who is using it, what it is being used for, how instrument findings are reported, and by whom the findings are used); and,
- Relevant peer-reviewed journal articles or full citations.

When submitting domains, please include, to the extent available:

- Detailed descriptions of question domain and specific purpose;
- Sample questions, in all languages available; and,
- Relevant peer-reviewed journal articles or full citations.

For all submissions, please also include:

A brief cover letter summarizing the information requested above for submitted instruments and domains, respectively;

Complete information about the person submitting the material, including:

- (a) Name;
- (b) Title;
- (c) Organization;
- (d) Mailing address;

(e) Telephone number;

(f) Email address; and,

(g) A written statement of intent that the submitter will grant to AHRQ the necessary rights to use, modify, and adapt the submitted instruments, items, and their supporting documentation for the development of the survey and its dissemination for AHRQ purposes, as described above.

FOR FURTHER INFORMATION CONTACT: Maushami DeSoto, M.Sc., Ph.D., MHA.

SUPPLEMENTARY INFORMATION:

Section 401(a) of the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA), public Law 111-3, amended the Social Security Act (the Act) to enact section 1139A (42 U.S.C. 1320b-9a). Since the law was passed, the Agency for Healthcare Research and Quality (AHRQ) and the Centers for Medicare & Medicaid Services (CMS) have been working together to implement selected provisions of the legislation related to children's health care quality. Section 1139A(b) of the Act charged the Department of Health and Human Services with improving pediatric health care quality measures. To implement the law, AHRQ and CMS have established the CHIPRA Pediatric Quality Measures Program (PQMP), which is designed to enhance select pediatric quality measures and develop new measures as needed.

The information sought in this Notice is being collected pursuant to the needs of the Children's Hospital Boston Center of Excellence for Pediatric Quality Measurement (CEPQM). It is one of the seven CHIPRA Pediatric Quality Measures Program (PQMP) Centers of Excellence and has been assigned the task of developing measures to assess aspects of the transition from child-focused to adult-focused care in young adults with chronic health conditions. To thoroughly carry out this task, the Center needs to identify and assess instruments or domains which already exist on this subject. Such measures will be considered in the development of a standardized instrument for voluntary public reporting by State Medicaid and CHIP programs and used by providers, consumers, other public and private purchasers, and others.

Existing instruments or domains submitted should capture adolescents' experiences with their health care, including the transition from pediatric to adult health care (for example, preparation readiness or evaluation of transfer). The survey development team is looking for items for which young adults or their parent proxies are generally the best or only judge; for example, the young adult or parent proxy can best say if the provider spent sufficient time with them or explained things in ways they could understand. Existing instruments that have been tested should have a high degree of reliability and validity; and evidence of wide use will be helpful.

Dated: April 8, 2013

Carolyn M. Clancy,
AHRQ Director

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